

# Perspectives on Self-Advocacy: Comparing Perceived Uses, Benefits, and Drawbacks Among Survivors and Providers

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**Purpose/Objectives:** To describe and compare survivors' and providers' views of the uses of and perceived benefits and drawbacks of survivor self-advocacy.

**Design:** A cross-sectional, two-group, mixed-methods survey.

**Setting:** Survivors were recruited from local and national registries and advocacy organizations. Providers were recruited from the University of Pittsburgh Medical Center Cancer Center and a regional Oncology Nursing Society chapter.

**Sample:** 122 female cancer survivors and 39 providers involved in their direct care.

**Methods:** Quantitative survey data were summarized using descriptive statistics, including means and frequencies. Qualitative survey data were collected and analyzed using content analysis techniques, and main themes were counted and summarized.

**Main Research Variables:** Perceptions of the uses, benefits, and drawbacks of female cancer survivor self-advocacy.

**Findings:** Survivors and providers perceived similar but distinct uses of self-advocacy. Survivors and providers generally agreed on the potential benefits of self-advocacy but had different views of the potential drawbacks. Survivors were most concerned with finding and making sense of information, that their questions would not be answered, and having a worse relationship with their provider; providers were concerned with increases in clinic time and difficulties developing treatment plans.

**Conclusions:** Although survivors and providers recognized similar benefits to survivor self-advocacy, they had different views of the uses and drawbacks of female cancer survivor self-advocacy.

**Implications for Nursing:** Attempts to increase self-advocacy among female cancer survivors must address survivors' and providers' views and apprehensions about self-advocacy.

Self-advocacy, defined as a cancer survivor's ability to get his or her needs met in the face of a challenge, is a critical skill for those facing the overwhelming disease and psychological burdens of cancer (Hagan & Donovan, 2013a, 2013b). Self-advocacy consists of three main skills: (a) making informed decisions, (b) finding strength through connection with others, and (c) communicating effectively with the oncology care team. Survivors need to be equipped with these skills to ensure that they can engage in their care, make personally meaningful decisions, and voice their concerns, particularly when it is difficult or uncomfortable (Walsh-Burke & Marcusen, 1999). Survivors can use these skills throughout their cancer experience to face their ongoing symptom management and meet their health promotion needs.

Protecting survivors' rights to self-determination is upheld as a professional duty by all healthcare providers. Provision 3 of the American Nurses Association's

(2011) *Code of Ethics* states, “The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient” (p. 1). Likewise, according to the American Medical Association’s Principles of Medical Ethics, “The relationship between a patient and a physician is based on trust, which gives rise [to] physicians’ ethical responsibility to place patients’ welfare above the physician’s own self-interest and obligations to others . . . and to advocate for their patients’ welfare” (American Medical Association, 2016, p. 4). Social workers describe a broader type of patient advocacy: “Social workers promote clients’ socially responsible self-determination. Social workers seek to enhance clients’ capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society” (National Association of Social Workers, 2008, p. 1).

Increasingly, cancer survivors want to be involved and consulted throughout their healthcare experiences (Arora, Ayanian, & Guadagnoli, 2005). Within oncology, survivor self-advocacy cannot only affect survivors’ decisions regarding their health care (Katz et al., 2005) but also can help ensure that survivors’ subjective preferences are valued during the clinical decision-making process (Collins et al., 2008). Therefore, the concept of survivor self-advocacy appeals to both survivors’ and providers’ goals. Despite survivors’ and providers’ apparent agreement on the importance of survivor self-advocacy, how each group defines the role of survivor self-advocacy in the patient–provider relationship remains unclear.

## Methods

The current study was a corollary study of a larger parent study (N = 317) that aimed to develop a measure of self-advocacy among female cancer survivors (Hagan et al., n.d.). The authors decided to focus the study on women, knowing that the communication, decision-making, and negotiation styles included within self-advocacy skills are known to differ according to gender. Survivors were recruited from the parent study. Results from the current study were completely separate from those of the parent study.

### Survivor Sample

For the parent study, the authors asked participants if they were interested in participating in future studies. Of the 181 participants who completed the online version of the study, 179 indicated interest in the current study. After the completion of the parent study, the research team sent interested participants a link to the survivor survey used in the current study. One hundred twenty-five (70%)

**Introduction:** Advocating for yourself means you are trying to get your needs, priorities, and desires met. There are many ways to advocate for yourself.

- What are the most important ways female cancer survivors advocate for themselves during their cancer experience?
- What are the potential benefits of patients advocating for themselves? Please select all potential benefits.
  - What is the likelihood of each potential benefit of patients advocating for themselves?
- What are potential drawbacks of patients advocating for themselves? Please select all potential drawbacks.
  - What is the likelihood of each potential drawback of patients advocating for themselves?

### FIGURE 1. Survey Introduction and Quantitative Questions

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survivors agreed to participate in the study and took the survey.

### Provider Sample

Healthcare providers were recruited through the director of the University of Pittsburgh Medical Center (UPMC) Cancer Center and a regional chapter of the Oncology Nursing Society (ONS). Emails were sent to potential participants describing the study and requesting participation. The email contained a link to the provider survey and described that the study was intended for all healthcare providers involved in the direct care of cancer survivors, regardless of their professional status.

Survivor and provider surveys were delivered using the Qualtrics web-based survey software, version 3092224. The survivors and providers who completed the survey were entered into a drawing (one drawing for survivors and one for providers) to receive a \$25 gift card. Human subjects protection was approved by the University of Pittsburgh’s Institutional Review Board.

### Measures

Prior to completing any survey items, the authors required survivors and providers to electronically sign a consent form, with an option to print the form for their records. Then, survivors and providers were asked to complete a brief sociodemographic survey, providing relevant information about their cancer experiences and professional roles, respectively. The main survey—developed by the investigator for this study—asked survivors and providers quantitative (rank-ordered and Likert-type items) and qualitative (open-ended) questions about their perceived uses, benefits, and drawbacks of survivor self-advocacy. To facilitate comparison, the same questions were asked to the survivors and providers with slightly adapted wording to address each group.

**TABLE 1. Sample Characteristics**

Characteristic	Survivors (N = 122)		Providers (N = 39)	
	$\bar{X}$	SD	$\bar{X}$	SD
Age (years)	54.2	10.5	47.3	11.4
Years since primary cancer diagnosis	7.1	6.2	-	-
Years in practice	-	-	10.7	8.8
Characteristic	n	%	n	%
<b>Gender</b>				
Female	122	100	36	90
Male	-	-	3	10
<b>Cancer diagnosis</b>				
Ovarian	49	40	-	-
Breast	47	39	-	-
Other	36	30	-	-
Multiple	15	13	-	-
<b>Most frequently treated cancers</b>				
Breast	-	-	18	46
Gynecologic	-	-	10	26
Breast and gynecologic	-	-	8	21
Multiple	-	-	2	5
Leukemia/lymphoma	-	-	1	3
<b>Professional role</b>				
RN	-	-	17	44
Oncologist	-	-	8	21
Nurse practitioner	-	-	4	10
Other	-	-	3	8
Physician assistant	-	-	3	8
Patient care technician	-	-	2	5
Patient navigator	-	-	2	5

Note. Because of rounding, percentages may not total 100.

Options for each question were written by the investigators and were based on their previous research and knowledge about self-advocacy (Hagan & Donovan, 2013a, 2013b). All questions were worded in a nonjudgmental and factual way, to promote honesty and limit social desirability bias in responses. Instructions to the survey briefly defined the concept of self-advocacy and cancer survivorship to ensure that the groups had the same general definition in mind while completing the survey.

Quantitative questions (listed in Figure 1) asked participants to consider (a) the most important ways female cancer survivors advocated for themselves, (b) the potential benefits of female cancer survivors' self-advocacy for themselves and the corresponding likelihood of each benefit occurring, and (c) the potential drawbacks of female cancer survivors' self-advocacy and the corresponding likelihood of each drawback occurring. In addition, participants completed open-ended qualitative questions asking them to describe their responses and add additional benefits and drawbacks.

Additional quantitative and qualitative questions were asked of survivors to assess their previous experiences of self-advocacy, including if they had previously advocated for themselves, when they had done this in their cancer experience, and when they had wished that they had advocated for themselves in their cancer experience.

Questions regarding the ways survivors advocate for themselves included six possible definitions commonly described by survivors and providers according to the research team's previous work. Participants were asked to rank order these options, and the number of respondents selecting an option as the most important way survivors self-advocate was analyzed. Questions regarding perceived benefits and drawbacks included seven options each and were dichotomized as yes or no responses. Participants could select yes to as many options that applied to them and were given the option to type in as many as three additional benefits or drawbacks. If participants selected yes to a benefit or drawback, they were asked to provide the likelihood of that benefit or drawback occurring. Questions regarding the likelihood of benefits and drawbacks were rank ordered from 1 (least likely) to 7 (most likely) to occur.

### Data Analysis

Survivor and provider survey responses were combined, and descriptive statistics were used to summarize survivor and provider sociodemographic information. Frequencies and percentages of responses to the self-advocacy questions were calculated. Student t-tests of mean differences were performed to detect statistical differences between survivor and provider responses to these questions. All analyses were conducted using SPSS®, version 23.0.

## Results

Table 1 describes healthcare provider and survivor characteristics. One hundred twenty-two women (98%) completed questionnaires. The mean age of survivors was 54 years (range = 19–71 years). Most survivors had either ovarian or breast cancer, although 15 different diagnoses were reported. Fifteen women indicated having more than one cancer diagnosis.

Thirty healthcare providers from the UPMC Cancer Center and nine members from the local ONS chapter completed the provider survey. Provider respondents represented a wide range of healthcare professionals; most (90%) were female, RNs (44%), and worked with breast and/or gynecologic cancer survivors.

### Definition of Self-Advocacy

Healthcare providers viewed self-advocacy as a way for survivors to manage their symptoms (n = 10, 33%)

and get support from their family and friends (n = 9, 30%). Only a few (n = 5, 17%) felt that survivors self-advocate primarily to maintain a good relationship with their oncology care team. In contrast, the top three ways women self-advocate according to survivors were to manage their cancer treatment (n = 29, 31%), manage their symptoms (n = 26, 27%), and maintain a good relationship with their oncology care team (n = 22, 23%). A few (n = 13, 14%) reported that self-advocacy was a way of getting support from their friends and family. Despite disagreeing on their main targets of self-advocacy, providers and survivors uniformly ranked participation in advocacy groups (providers [n = 2, 7%], survivors [n = 1, 1%]) and addressing survivors' financial problems (providers [n = 1, 3%], survivors [n = 4, 4%]) as the least frequent applications of self-advocacy.

The 61 survivors who submitted qualitative comments noted several additional ways in which women self-advocate. The most frequent themes included cancer survivors reaching out to others and/or joining support groups (n = 15), educating themselves (n = 14), working with their employers (n = 6), managing their health information (n = 3), and asking their healthcare providers questions (n = 3). Of the 11 providers who submitted additional responses, four referred to survivors educating themselves. Others mentioned the need for survivors to prepare for medical appointments and discuss their priorities with their providers.

### Previous Experiences

Ninety-four survivors (91%) reported having to advocate for themselves during their cancer experience. Survivors had to self-advocate most frequently when experiencing symptoms or side effects from treatment (n = 63, 67%) followed by the transition off of treatment (n = 59, 63%), and when developing a treatment plan (n = 55, 59%). Few participants wrote in additional responses for these items.

### Benefits of Self-Advocacy

Figure 2 lists survivors' and providers' perceived benefits of survivor self-advocacy. All providers thought that self-advocacy promoted survivor self-management, and the majority thought that it improved patient satisfaction (n = 35, 90%), health outcomes (n = 34, 88%), patient-centered care (n = 34, 88%), and patient-provider relationships (n = 32, 83%). Few providers (n = 11, 28%) thought that

self-advocacy reduced healthcare costs, and more than half (n = 21, 53%) thought that self-advocacy improved the efficiency of healthcare delivery. Survivors generally agreed with providers, but more than half (n = 26, 67%) thought that self-advocacy improved the survivor's relationship with their healthcare provider. Providers were more likely than survivors to view self-advocacy as leading to survivor self-management, improved patient-centered care, and more efficient healthcare delivery. Survivors were more likely than providers to view self-advocacy as leading to reduced healthcare costs.

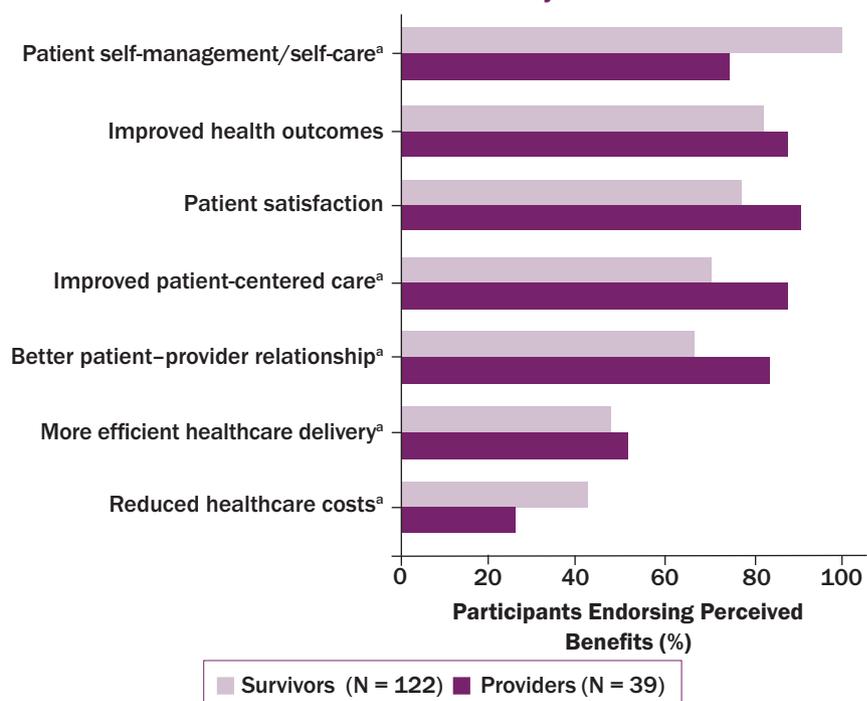
Survivors and providers agreed on the likelihood of each of these benefits, and no significant differences were detected (Figure 3). Both thought that improved healthcare outcomes and patient-centered care were the most likely benefits and that reduced healthcare costs and efficient care were the least likely benefits.

Survivors submitted additional benefits of advocacy, including survivors being better informed, feeling empowered, having a sense of control, and feeling connected to other cancer survivors. Providers also submitted additional benefits of self-advocacy, including survivors having additional resources and people to reach out to, as well as improved control, empowerment, and hope.

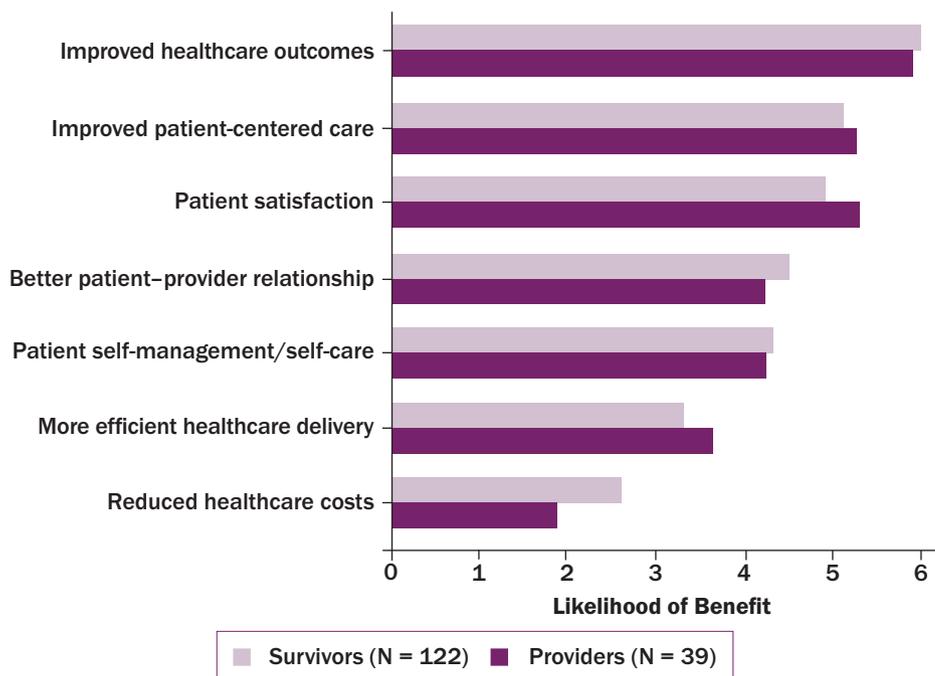
### Drawbacks of Self-Advocacy

Figure 4 lists survivors' and providers' perceived drawbacks of survivor self-advocacy, which differed

**FIGURE 2. Perceived Benefits of Self-Advocacy**



<sup>a</sup> Statistical difference between-group means at alpha = 0.05



Note. Survivors' and providers' perceived benefits were mean rank ordered from 1 (least likely) to 7 (most likely) to occur.

**FIGURE 3. Likelihood of Perceived Benefits of Self-Advocacy**

statistically between the groups. The most frequently selected drawback by providers was increased time during clinic visits ( $n = 18, 45\%$ ). Providers also reported drawbacks of not being able to answer survivor questions or respond to their needs ( $n = 16, 41\%$ ) and an increased number of survivor calls and visits ( $n = 15, 38\%$ ).

The most frequently selected drawbacks of advocacy for survivors were not being able to get their questions answered or needs met ( $n = 56, 54\%$ ) and finding and dealing with health information ( $n = 54, 52\%$ ). Survivors also were concerned that self-advocacy would worsen their relationships with their healthcare providers ( $n = 49, 48\%$ ).

Providers and survivors agreed on the likelihood of these self-advocacy drawbacks (see Figure 5). The most likely drawback was dealing with health information presented by survivors. Providers were much more likely to perceive increased time during clinic visits to be a drawback compared to survivors ( $\bar{X} = 6.1, SD = 0.9$  versus  $\bar{X} = 4.4, SD = 1.4, p < 0.001$ , respectively).

Survivors submitted additional drawbacks of advocacy, including potential problems working with their healthcare providers, understanding or being overwhelmed by medical information, stress related to increased responsibilities, and problems navigating the healthcare system. Providers discussed the drawback of survivors wanting to use

non-evidence-based treatments or becoming sidetracked by nonstandard care.

## Discussion

Survivors and providers largely agreed on the benefits of survivor self-advocacy, including improved health outcomes, patient satisfaction, and more patient-centered care. However, survivors and providers demonstrated marked differences in their views of how women self-advocate and the perceived drawbacks of self-advocacy.

Interestingly, the groups perceived the intent or end goal of self-advocacy quite differently. Survivors thought that self-advocacy helped them manage their treatment and maintain a good relationship with their healthcare providers, but providers saw self-advocacy

as a way survivors managed their symptoms and side effects of treatment or received social support.

The authors gave participants an extremely general definition of self-advocacy, suggesting that the survivors and providers had preconceived ideas about what self-advocacy was and was not, and that those definitions may have differed. Although the authors systematically developed a theory of self-advocacy among individuals with cancer (including significant input from survivors) through previous research, it may not have been the same definition held by survivors and providers. Therefore, researchers must consistently and clearly define survivor self-advocacy when developing interventions and recognize others' prior conceptualizations of self-advocacy.

Survivors and providers tended to agree on the likelihood of the potential benefits and drawbacks of self-advocacy, suggesting that they recognized the same possibilities of and barriers to survivors engaging in their care. Although the groups agreed that survivors could have better health outcomes if they advocated for themselves, both thought that the efficiency of care and the reduced costs of care were the least likely benefits.

Differences also existed in the perceived drawbacks. Survivors were mostly concerned about the added responsibility of managing health information and the possibility of not having their questions answered by their providers. They also reported

concerns about self-advocacy negatively affecting their relationships with their providers. Providers were likewise concerned about not being able to answer survivors' questions and concerns but were mostly concerned about the added time with survivors and longer clinic visits, which could be related to providers' lack of time or uncertainty about the types of questions survivors would ask. Survivors were least concerned with the issues of clinic time and time spent with healthcare providers or on developing treatment plans, likely because survivors appreciate more time and attention with their providers. These distinct drawbacks reported by survivors and providers represent each group's distinct values and must be addressed while implementing strategies to improve survivor self-advocacy. Interestingly, survivors and providers generally believed that advocating improved the patient-provider relationship but also reported concerns about the negative impact it could have on the relationship. This finding likely represents the value both groups place on their relationship with each other, and their mutual desire to support but not to disrupt this vital relationship.

However, not all cancer survivors want to be active decision makers in their care (Beaver, Bogg, & Luker, 1999; Leydon et al., 2000). Survivors are often overwhelmed by the number of decisions and changes that occur with a life-changing diagnosis such as cancer. While respecting survivor autonomy, providers should encourage survivors who are willing and able to engage in self-advocacy behaviors to do so. Survivor hesitation regarding decision making may be reduced by oncology clinicians' support and help in directing their decisions (Brown et al., 2012) or even inform them of what times their voice is most relevant and necessary during the treatment process. Providers might openly address survivor concerns about managing health information, negatively affecting their relationship with their healthcare provider and receiving answers to their questions. By overtly creating an environment that supports survivor involve-

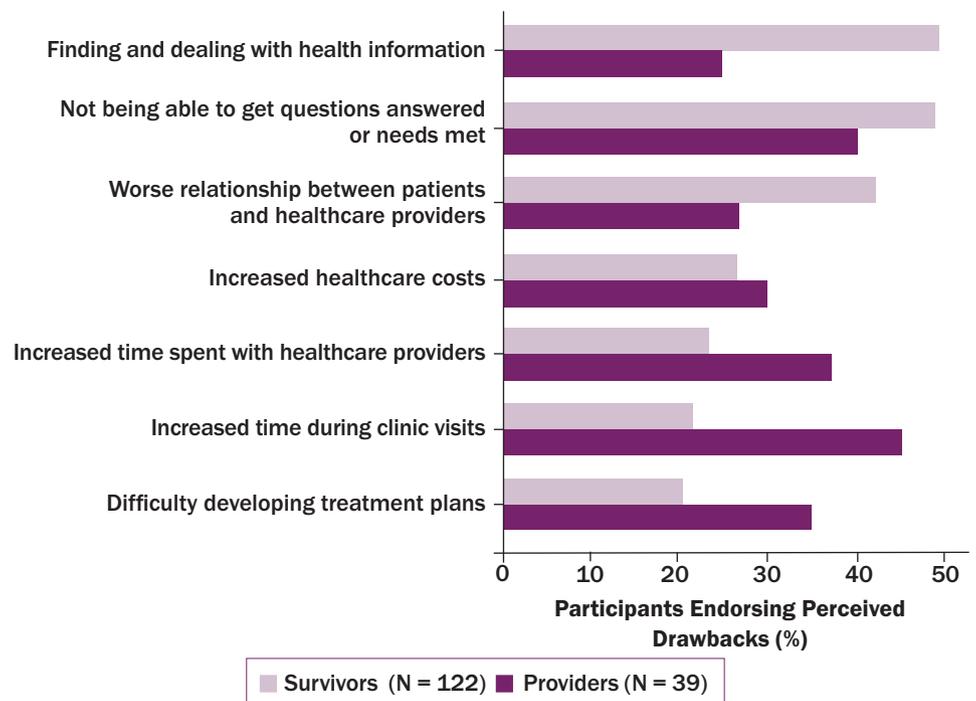
ment, providers may empower survivors to engage in self-advocacy.

## Implications for Nursing

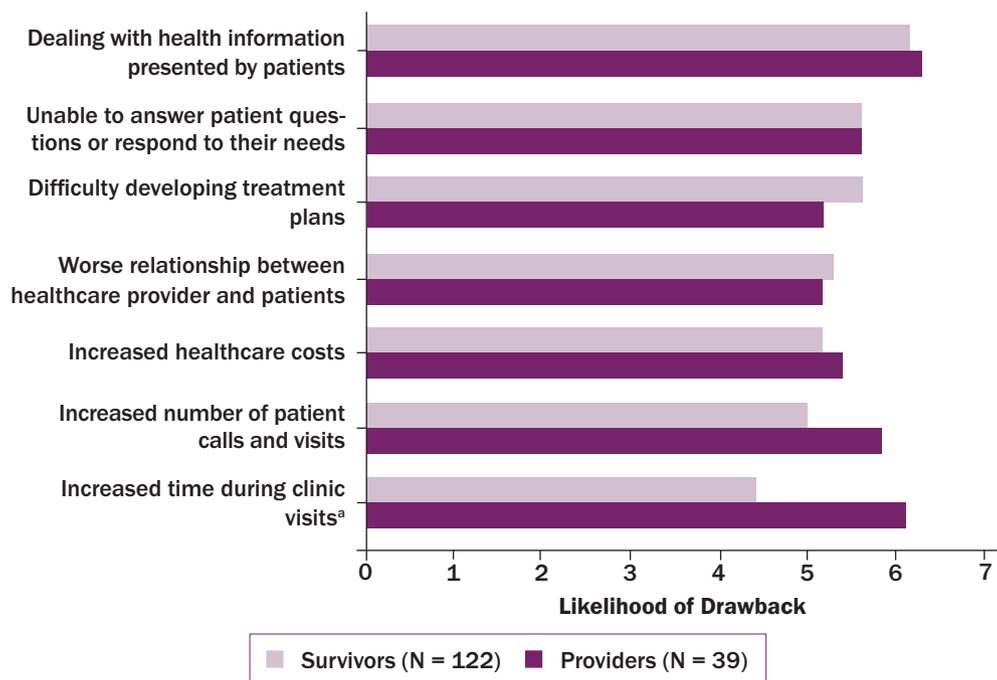
Survivor and provider concerns about self-advocacy must be addressed in an attempt to improve survivor self-advocacy, particularly by nurses. As the most trusted healthcare professionals, nurses bond with survivors and represent a central link between survivors' experiences with various healthcare providers (Saad, 2015). Providers must appreciate survivors' desires to bolster their relationships with them through self-advocacy. The provider-survivor relationship may provide survivors with a sense of control and connection, a key means by which to reduce stress caused by a cancer diagnosis and treatment (Taylor, 1983). Providers' desires to improve survivor self-management and their concerns about time and developing treatment plans must also be addressed. Interestingly, both survivors and providers were concerned about survivors' questions being answered, suggesting that both survivors and providers (e.g., nurses, physicians) may hesitate to ask and elicit questions, respectively.

A partnership between survivors and providers can grow as they understand what the other expects, wants, and fears regarding survivor self-advocacy. Given that survivors and providers both respect the

**FIGURE 4. Perceived Drawbacks of Self-Advocacy**



Note. For all perceived drawbacks, the statistical difference between-group means at alpha = 0.05



<sup>a</sup> Statistical difference between-group means at alpha = 0.05

Note. Survivors' and providers' perceived benefits were mean rank ordered from 1 (least likely) to 7 (most likely) to occur.

**FIGURE 5. Likelihood of Perceived Drawbacks of Self-Advocacy**

potential for survivor self-advocacy to improve survivor care and experience, communication about their respective desires and hesitations can lead to mutually beneficial action. Systematic and structural barriers of survivor self-advocacy listed by both groups (e.g., time, delivery, cost) could be addressed within the healthcare delivery system. If providers receive organizational support, they may be more likely to help survivors advocate for themselves.

This research study reflects trends regarding survivor self-advocacy. The authors' finding that survivors endorsed self-advocacy as a way to manage their treatment reflects national trends of cancer survivors' desires to be involved throughout their cancer care experience (Chewning et al., 2012; Say, Murtagh, & Thomson, 2006). Although providers in the current study reported overall positive views of survivor self-advocacy, research has demonstrated that nurses, social workers, and other clinicians frequently report barriers to advocating for survivors, including lack of professional skill, not being eager to engage in advocacy, and lack of institutional support (Jansson, Nyamathi, Heidemann, Duan, & Kaplan, 2015; Vaartio-Rajalin & Leino-Kilpi, 2011). These barriers are analogous to those reflected in the current study, including concerns about the ability to answer questions and develop treatment plans, both of which require refined skill and dedicated effort on the part of providers. Ultimately, and most impor-

tantly, this study confirms that survivor and provider concerns about upsetting the patient-provider relationship (Hillen, de Haes, & Smets, 2011) and the length of clinical visits (Thorne, Hislop, Stajduhar, & Oglov, 2009) must be addressed to improve the survivors' ability to self-advocate and the acceptance of self-advocacy by healthcare providers.

### Limitations

The convenience sample of survivors were from the parent study, and providers were from one medical institution and one professional organization. Also, only female survivors who completed the online version of the parent study were recruited; women who

completed the paper version were known to have lower self-advocacy scores on the Female Self-Advocacy in Cancer Survivorship Scale (Hagan et al., n.d.). These women may have reported different benefits and drawbacks of self-advocating that were not noted in the current study. Self-report surveys limited the number of responses, although many participants took advantage of the option to write in additional responses. Also, the large number of nurses in the provider sample made the results more generalizable to nurses rather than to physicians or other healthcare providers, who may hold different opinions about survivor self-advocacy.

### Conclusion

This study compared cancer survivors' and providers' perceived benefits and drawbacks of survivor self-advocacy. Although both groups noted several common advantages of self-advocacy, including improved self-management and patient satisfaction, both groups also reported concerns about how survivor self-advocacy would change the patient-provider relationship and clinic visits. Shedding light on these hesitations and barriers allows survivors and providers to engage creatively in ways to address the perceived drawbacks of survivor self-advocacy. The authors' ultimate goal was to foster collaboration among survivors

## Knowledge Translation

- Survivors and providers perceive different drawbacks of survivor advocacy for their needs and priorities.
- Providers have concerns about clinic time, answering survivor questions, and developing treatment plans.
- Promoting survivor self-advocacy requires addressing both survivors' and providers' conceptualizations of self-advocacy and ensuring that their apprehensions are adequately addressed on interpersonal and structural levels.

and their oncology care teams so that survivors can advocate for their needs and care teams can provide them with the highest quality patient-centered care possible.

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